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ABSTRACT

The scripts are intended for broadcasting in translation to villages in Pakistan to raise awareness about disabilities and to provide practical advice to parents of disabled children. The initial broadcast emphasizes the essential humanity of all disabled persons, while subsequent broadcasts address issues in raising children with mental retardation, epilepsy, physical disabilities following polio, blindness, and deafness. Interviews with the children or young adults, doctors, and family members are included. (CL)

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REHABILITATION BROADCASTS

TO RURAL VILLAGES

[Draft]

EC 162 119

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15th January 1984

Mental Health Centre
Mission Hospital Peshawar
NWFP Pakistan

Draft Broadcasts on Rural Rehabilitation for Disabled Persons

Dear Barbara B Turner

The enclosed draft scripts are the first half of a series written for broadcasting in translation to Pakhtun villages. For disabled persons in such villages, specialist rehabilitation knowledge and facilities are non-existent, as is the case for some 70% of all disabled persons in the world. Financial margins within families are extremely limited. The advice given is intended to be congruent with the restraints on resources while appealing to the commonsense and practical wisdom of the audience. Perceptions about disability that are commonly found in economically backward areas are discussed incidentally.

Potentially the series may have a wider audience, with some adaptation for local conditions. You and your associates are most welcome to make any use of these programs, whether as written or in modified form, by duplication, broadcast, publication or any other method. If there is sufficient interest and response I will send out the second half of the series to those who request it, in a few months' time. I expect to include material on Prevention, further aspects of Mental Retardation, Cerebral Palsy, Speech Problems and Behavioural Disturbance.

Yours sincerely,

M. Miles

M. Miles

Administrator, Mental Health Centre

Project Consultant, FAMP/UNICEF Community Rehabilitation Development Project

BROADCAST NO. 1 : ONE IN TEN IS DISABLED

Out of 10 fingers and thumbs on your two hands, is every one equally big and strong? Of course not! For most people there is one finger that is smaller and weaker than all the rest: the little finger on the left hand. Does that mean we should chop off the small and weak finger? I don't think so! It surely serves its purpose along with all the other parts of the body.

One out of ten is especially small and weak. And that goes for children too. All over the world we find that something like one child out of every ten children has a disability. Some children are physically crippled :- maybe their legs are not working, or one side of the body is paralysed. For other children the problem is that they are blind or deaf. Then there are some children who are not able to learn things in the normal way. We see sometimes a big boy who still speaks like a baby, or who has not learnt to tie the knot of his shalwar cord or button his shirt. We say that these children are "mentally retarded".

Because these children have some special difficulties in life, does that mean we should ignore them, hide them or mock them? By no means! On the contrary, if such a child belongs in our family or in our community, it is our special responsibility to care for and train that child. Just like the fingers on our hands, we do not hide one of them away simply because it fails to match the size and strength of the others. All the ten digits appear together, playing their part in everyday life.

In the same way, if you have a child who is weaker because of his disability, he should still take part in everyday life as far as possible. Many famous people have suffered a disability themselves, or have had a disabled child. One President of the USA was physically disabled during his term of office, and went about in a wheelchair. Another U.S. President had a mentally retarded sister. The President of Pakistan at this moment has one little daughter who is deaf, and he is not ashamed of the fact. It can happen to a big, wealthy family, or to a poor, small family, that one of its members is disabled.

There is one thing that all disabled people have in common. Whatever their disability, they all agree on one point. And it is this: it is a sad thing to be blind, crippled or whatever, but a far worse thing is to be rejected by one's family, pushed away and scorned by the neighbours. Each person suffering a disability has the same thing to say: I am a complete person, I am Mohammed Ali, I am Razia Begum, I am Zaffar, I am Nur Jehan. The fact that my legs do not work, or my hearing is defective, does not mean that I am only half a person. I am a complete person. Do not reject me or despise me.

Even more this is the case with a growing child who suffers from a disability. Every child who is growing up desires to please his parents and to win their approval. In order to grow up with a well-balanced mind and personality, in order to develop a good moral character, all children need the encouragement

and approval of adults, whether of their parents or of their uncles and aunts, their neighbours, their teachers, the local leaders and maulvis. By means of such approval and encouragement the growing child learns what is acceptable and right behaviour. He learns also to avoid doing things which cause anger and annoyance of his family and neighbours.

But imagine now the position of the disabled child. What does he hear from his parents, if they have not thought carefully? He hears them lamenting and complaining about him. "Oh," they say, "Tariq is crippled, he cannot walk, how will he ever manage to earn his living? He is not much use for anything." "Alas," they complain, "little Bilquees has lost her eyesight, she can neither help her mother in the house nor can she go to school. Who will marry her when she becomes a woman?" The deaf child or the mentally retarded one sees the neighbours shaking their heads or laughing at him.

All these reactions by the adults are very depressing for a disabled child. He feels that he has failed to please his parents. He learns that the neighbours do not like him, he is not accepted by the local community. This is a crushing burden to load onto a child who is disabled or retarded. Of course, people do not deliberately try to crush such a child. They do it thoughtlessly. It is the result of a failure to think, a failure to understand the child's point of view.

What is to be done? After all, it is undeniable that parents will be upset if their child turns out to have a disability. It is discouraging for them. Their relations will argue about whose fault it is, whether the father's side of the family or the mother's side. Such disputes are pointless, since they do not change the actual fact that the child is disabled. All that can be achieved by such arguments is to set the man and wife against each other.

Where does this lead us? We can see one pair of hands with a small, weak finger pushed away or crushed down by the fingers next to it, while the other fingers wrangle with each other and twist around arguing and snapping! Nothing of any use will be done by that pair of hands. Let us look at a sensible pair of hands instead. All the fingers and thumbs are working together, each according to its strength and position. Now we see some useful work being done!

If you have a child who suffers from a disability, or if you know of an adult person who is disabled in your village or mohalla, try to look at them in this light. First of all that child or adult is a complete person, even if part of the body does not work properly. Secondly, that person has the same requirements as any other person: to belong to his family and be accepted and loved by his kin; to have food, drink, clothing and shelter; to learn some trade or occupation with which to contribute to the common good and to earn his daily bread. Even if one sense or part of the body is missing, there are many things which a disabled person is capable of doing. If he is given some encouragement and help at the start, he will find his place in the community.

In the broadcasts following this one we will be looking at the special problems and possibilities attached to the main types of disability. We will be talking about families who have a deaf child, a physically disabled child, a blind child or a mentally retarded child. We will discuss the sort of actions the parents can take to help in each case. We will also look at some other common problems, such as the child who has fits, the child who stammers or cannot say his words properly, the child who wets his bed every night. These are all common problems experienced by children all over the world. Some of the problems cannot be cured, but all of them can be relieved in some measure. And for every one of them the solution begins when the big strong fingers on each hand decide to accept and help the small and weak finger.

BROADCAST NO. 2 : THE MENTALLY RETARDED CHILD

Parents: Doctor, we want to ask your advice about our boy Tariq. He is very weak in his mental ability, compared to our other children. He is six years old now, but his behaviour is more like that of a baby. He says only a few words, and he cannot put on his clothes without help. We tell him everything about twenty times, but even then he does not understand. Quite often he flies into a rage over nothing.

Our next child is only three, but already he can do more than Tariq. When Tariq was very small he had a severe fever for a week, and although he recovered he has never made much progress since then. Do you have any medicine to make his brain work faster?

Doctor: Well, I've given Tariq a check-over and it is clear that he is mentally retarded. Mental retardation is a permanent condition. It is not a temporary illness that might be cured. Medicines may help some of his behaviour problems but they will never make him normal. Even the best qualified doctors cannot cure him and there is no point in wasting money on expensive treatments. His mind will not develop as fast or as fully as that of other children, and he will always seem younger than other children of the same age.

There are different degrees of mental retardation : there are retarded children who can do less than Tariq, while others can do more. It is simply a fact of human life, that out of every hundred babies, two or three are mentally retarded. Some babies are born wealthy, some are born in poverty. Some are very clever, others have weak brains. It is not always the rich and the clever who lead the happiest life. The best thing is to treat your son as normally as possible and see how he turns out.

Parents: But what are we to do with him? It is not normal to have a boy like that. There must be something we can do.

Doctor: Certainly, there are many ways you can help Tariq. The mentally retarded child has a special need to be loved by his family. Love and affection will help him to feel that he is worth something and will bring out the best in him. Whereas if he is rejected or teased he will become frustrated and destructive. Show him as much affection as you show to his brothers and sisters. Gifts and treats are often seen by children as signs of love and acceptance, so make sure your retarded child received his equal share. Make it clear to him and to other people that you are not ashamed of him.

At the same time, loving him does not mean being too indulgent. Because the mentally retarded child learns things very slowly it is important for there to be consistent discipline. Rules for your child should be the same every day,

and his grandparents, uncles and cousins should also apply the same rules to him. It is better not to chop and change, however much fuss he makes and however much people feel sorry for him. In the long run it is better for him to learn the correct behaviour that is expected of him. Be sure to reward him and tell him what a good boy he is as soon as he obeys you.

When you take your meal, that is a good time for Tariq to learn new words and good behaviour. He will be eager to get his food and will make a greater effort to understand what you want. Take every opportunity of talking in a straightforward, ordinary way to Tariq. You should use normal words, not too fast, and ask questions of him and help him to make his answers. Let him listen to the radio. Let him join in singing songs. Say prayers aloud with him.

Every child needs the opportunity to learn from his surroundings, to handle different things, to talk about what he sees and does. Ordinary things that you have around the house can help him to learn. For example, let him play with a bucket of water and several plastic containers. Give him a cooking pot and show him how to drum on it with a small stick. Let him practise tying knots in a piece of string. He will need to try 20 or 30 times things that another child would do only 2 or 3 times. Take him to the bazar and talk to him about everything there is to see. He should always accompany you on family celebrations, weddings and visiting relatives. Whenever he behaves well, or when he learns a new word, always praise him straight away. Then he will be encouraged.

Having a mentally retarded child can put quite a strain on the whole family and especially the mother. The need for close supervision all the time may make everyone in the family more irritable. Your child's brothers and sisters may become jealous because he is taking up more of your time. Make sure they do not tease him or mock him. A wise parent will give special attention to the other children too, and see to it that everyone in the family gets away from the problems from time to time.

Parents: Yes, but how long will this go on for? What will happen when he is grown up?

Doctor: That is not an easy question to answer. A great deal depends on how successfully you integrate Tariq into your normal everyday life. Certainly he will never be a well-educated man when he grows up, and it is likely that he will always need some help in managing his affairs. But apart from that, if he receives enough loving care and encouragement now as a child, there is no reason why he should not learn enough, little by little, to make himself useful as an adult.

I know the next question you are thinking of asking: Can he get married and have children? This is another difficult question, because each individual is different and unique. He is 6 now, and who can tell what he will be when he is 26! But there is quite a good chance that he will be able to marry and that his children will be of normal intelligence. He will need a very helpful girl to marry him :- get him a wife who is a little older than usual, maybe 20 or 22.

As a general rule, all through his childhood and becoming grown up, you should try to treat Tariq in as normal and ordinary a way as possible. Don't do everything for him, if there are things he could do for himself. It will take longer to start with, and you may lose patience with him, but in the long run it will help him to learn more. Suppose he has some difficulty putting on his shirt. Let him get as far as he can before you help him. Next, you help him with the difficult part. Then leave him to finish by himself. Praise and reward him for everything he achieves by himself, and avoid teasing and making any fuss over the parts he has not yet learnt.

Parents: Doctor, it seems to take so long for him to learn even the simplest things. He does not seem to know any more now than a year ago.

Doctor: What you say is perfectly true, and there is one thing you can do about it: try to keep a record of what Tariq actually can do, and then you will see that he is making progress even if only slowly. Try to get it written down every month or so exactly what he can do. Another way is to make it a family game. Everybody thinks of all the words Tariq can use, and calls out each one. You put one small stone into an empty tin for every word Tariq can use. Then you seal up that tin. Everybody should encourage Tariq to learn new words, and then after a few months you play the game again, and see how the number of stones grows bigger each time.

Of course, you need a lot of patience and kindness. But remember, God is merciful and patient with every one of us.

BROADCAST NO. 3 : PEOPLE WHO HAVE FITS

Today we are going to talk with Malik Mohammed Abdul about one of the health problems of his village : people who have fits. (Cut into conversation with tea cup clinking etc.)

Malik: .... so there are about four or five adults and children, out of 6,000 people in our area, who have fits badly. Perhaps there are more who have small fits which are not noticed. In times past we used to think that these people had a djinn. Now we have learnt that it is simply a physical condition which can be treated with drugs.

Interviewer: Out of these two explanations, which one is believed by the people of your village?

Malik: Some believe one thing, some believe the other. The more educated people, those who have been to school or have gone away and lived for some time in the city, they understand the modern approach : that having fits is a medical condition which can be treated. But still the ordinary people are afraid when they see a man fall down, out of control of himself, lashing about with his arms and legs. I myself used to think that there must be a djinn causing such an alarming effect.

Interviewer: But you have changed your mind now?

Malik: Yes, I now know that it is a matter for medical treatment. I will tell you what caused me to change my mind. My cousin has a daughter who used to have fits. Her fits were not of the most violent sort, but she would sit down suddenly and her face would become blank for half a minute. Sometimes she would soil her clothes with urine during the fit. When this problem was first noticed, my cousin was ashamed to have such a child. Nevertheless, the girl was normal in every other respect. So on one occasion when he visited the city he took his daughter with him and they consulted a pediatrician. Some tests were done at the hospital, and then drugs were prescribed.

Interviewer: What effect did the drugs have?

Malik: When the girl started taking them the fits stopped. Beforehand she was getting one or two mild fits every day, but after taking the drugs she has only an occasional fit, perhaps once in two months. So after a few months my cousin said, "The girl is cured. Thanks be to God!"

Interviewer: What happened then?

Malik: My cousin thought that the problem was finished, so he stopped buying the drugs for the girl. But after another month, her fits began coming again. He took the girl a second time to the doctor. More tests were performed, and the doctor said that the girl would be okay but only if they continued with the drug on a regular basis and did not stop it. He also said to bring the girl every six months for a check-up.

Interviewer: That was good advice. The drugs should be taken regularly, and the person with fits should check up with the doctor after an interval. How is your cousin's girl these days?

Malik: She is fine now. This took place four years ago, and I took careful note of what happened. Since the drugs are working and the problem is under control, I thought about this whole matter and I came to know for sure that the fits are a medical problem which can be treated. Now my cousin has arranged for his daughter's marriage, which will take place in the autumn.

Interviewer: What about the other people in the village who have fits?

Malik: I sent word to the heads of their families, that they should get those people treated by the medical personnel. In some cases they have done so, whereas in other cases they have given some excuse or have delayed taking action. I have called one of the men who used to have fits and you may ask him any questions. He is waiting outside. (calls) "Ijaz, present yourself".

Ijaz: Peace be with you.

Malik and Interviewer: And upon you be peace.

Malik: Ijaz, we wish to know whether you are having any problem now with fits.

Ijaz: God be praised, the problem has ceased since I went to the doctor and began taking the drugs he prescribed. Previously it was very difficult for me to work. In my family we are builders by profession, and it happened on one occasion that I was repairing a roof. I suffered a fit, and fell from the roof and hurt myself badly. On another occasion I was using an axe to cut wood, and I had a small fit which caused me to lose concentration. As a result I cut my foot with the axe. In those days my family did not wish me to continue working, because they were afraid of a serious accident occurring.

Interviewer: They had good reason to fear. So what decision was reached?

Ijaz: In the first place we visited some holy men and hakims and tried the prayers and treatments, but with no success. I was not willing to continue visiting these people, because I wished to avoid too many people coming

to know about my problem. Some of our neighbours used to make derogatory remarks about me. On one occasion when I was younger, I had a fight with another man because he said I was mad. It is true that I used to become irritable and badtempered before having a fit, but I was not mad. He had no right to make such a remark.

Malik: That was all a long time ago. People do not say anything about you now.

Interviewer: So when did you get medical treatment?

Ijaz: After a lot of discussion with the family my father and my uncle said that I must not work with them in building and carpentry until I had got myself treated. Thus I came to know that I should see the doctor. When I did so, he gave me first of all some drugs which stopped the fits but those drugs also made me sleepy. I went again to him and asked for some other drug. The doctor told me that I should take the same drug, but less often. He prescribed three pills instead of four. When I tried this number the fits were not present nor did I feel sleepy. So that was successful.

Interviewer: That is an important point. Each person is different from every other person, and the doctor has to balance the quantity of drugs in order to get the right effect without any unwanted side effects.

Malik: Ijaz, do you know of any other person who has fits?

Ijaz: I know of a boy on the far side of the village who has very violent fits. He is also mentally retarded. The family were hiding him, and even the neighbours did not know of his existence. I came to know about him because the family called me to construct additional quarters in their house. They had tied up this unfortunate young boy in the women's quarters, but he got himself untied and came into the men's quarters and was shouting nonsense. Then they had to tell me about him, although they were ashamed and had hoped to conceal him. His head was much bruised because he often fell down while having a fit.

Interviewer: What did you say to them?

Ijaz: I told them that there was no reason to tie the boy, and that they should not feel ashamed of him. I told them that they must take the boy to the doctor, and they would get some drugs which would control his fits. The boy actually fell down in a fit while I was present, and the family stood there doing nothing. I showed them how to loosen any tight clothing he was wearing, and to roll him onto his side and place some cloth under his head so that he would not bang his head on the hard floor. They asked me : Are you a

builder or are you a doctor? But I told them that all these things are sensible actions which any person can do very easily. So, by explaining it to them, I convinced them.

Interviewer: You did well, Ijaz. It is the business of every person to have this knowledge and to take these actions. By doing so, the problem of fits will become manageable and the ordinary people will no longer fear djinns or make malicious comments. It is true that some children who have fits are also mentally retarded. But there are many people who have fits and who are perfectly normal in every other way. In either case, treatment is possible and should be started without delay. In the case of a child who damages his head when he falls, it is possible to make a little helmet out of sponge rubber and cloth or leather, which gives some protection to the head. But in other respects the child who has fits should be treated normally. It is not possible for one person to catch fits from another person, and there is no reason to keep people out of the normal life of the community simply because they have fits.

BROADCAST NO. 4 : PHYSICALLY DISABLED CHILD (FOLLOWING POLIO)

If you ask a physically disabled child what he wishes for when he is day-dreaming, he may say that he would like to be a champion sportsman of his village. If he cannot be a sportsman he would at least like to be able to walk and run like other children.

There was once a little girl whose leg was withered, and her family gave her all possible care and treatment by their own efforts. That girl grew up to become a world champion runner. Her name was Wilma. She was a black girl, from a family of American negroes. When she was small, she fell ill with poliomyelitis. After the fever passed, one of her legs was not working. Her family were poor people, and they could not afford any special treatment.

They took Wilma to a doctor, who told them that they should give exercise and massage. They asked the doctor "Haven't you got any medicines that will cure her? We will try to find the money." He said to them "There is no medicine whether you are rich or poor. You yourselves are going to be the best medicine for Wilma." So the family agreed together that they would all do whatever lay within their power to help Wilma.

They used to take turns in massaging Wilma's paralysed leg. They would put a little oil on their hands and then rub the leg firmly along its length with both hands. Then they used to help the leg to stretch and bend, and move the foot from side to side and up and down. They would do this gently at first, because it could be rather painful to start with. They also helped Wilma to exercise her other leg and her hips, in order to strengthen both sides of the body equally.

When they started massaging Wilma's leg and giving it exercise, a little swelling came up at the knee and at the ankle. So they stopped exercising and went to ask the doctor. He said, "That's normal, that's okay, carry on with the exercises. There will usually be a little swelling to start with, and it will disappear after a few days if you carry on massage and exercises. But if the swelling gets worse, then you should stop."

Wilma's family took the doctor's advice, and carried on giving massage and exercise three or four times per day. After a few days the swelling went down. Slowly Wilma began to get some feeling back in her leg. Everyone got quite excited when she was able to wiggle her foot without help. They said to her, "Wilma, we're going to buy you a skipping rope for your next birthday, and you have to get fit and well to use it. You will skip up and down the street.

Wilma's birthday was six months away. Wilma asked herself, "Will I ever be able to skip and run like other kids? If ever I am able to run, I will run all day and all night, faster than anyone has ever run before." She said to her sister "You had better start training yourself, because I am going to do a lot of running. Now help me move my leg." Together they swung the leg up, down, bend at the knee, stretch out again, across and back, flexing and

straightening the ankle. Slowly, week by week, the strength came back into Wilma's leg and the muscles began to show up.

Wilma's birthday came and went, without her being able to skip. It took a longer time than her family had hoped before she could even walk. Wilma had to have a caliper to strengthen her leg before she could walk. Her family were poor people and they could not afford an expensive caliper. They made a splint out of wood and bandages and tied it behind the knee, so that Wilma could walk without her knee buckling and bending. They also made her a pair of wooden crutches with padding to go under her arms, to help her walk.

One of Wilma's uncles worked in a garage with welding equipment. He said, "I can make a better splint than you have there, by welding metal rods." So he took a light iron rod and welded two flat iron strips bent in a half circle, to support the leg above the knee and above the ankle. He padded the supports with a piece of rubber and sewed leather around the rubber to make it comfortable. They strapped it to Wilma's leg and helped her to stand up. "Is it good?" they asked her. "No," said Wilma, "it pinches my leg just here."

So they tried again, fixing the padding in a different way. "Is it comfortable?" they asked. "Yes," said Wilma "it is comfortable, but now it is so loose that it does not support my knee and so it will be of no use!" Wilma's uncle measured the leg again and took the caliper back to his garage. He cut one of the supporting strips, and welded it higher up and at a different angle. Then he put the padding back on and brought it to Wilma. Three more times they tried it, and either it did not fit or it was too loose. Each time Wilma's uncle said, "Don't worry, we'll get it right next time." Finally he brought the caliper and Wilma put it on and said "Okay now it is right. Now watch me walk."

With her sisters holding each hand, Wilma staggered across the room. It took a lot of effort. It took even more effort before she could walk down the street. Months passed of hobbling about with calipers and crutches before Wilma was able to walk without these aids. In fact, because she was growing bigger, her uncle had to come again and adjust the caliper to take account of her legs growing longer.

The family called on the doctor again and told him "Wilma is walking, but she's not very strong. She gets tired very quickly." The doctor said "You have all done a good job for Wilma. Only one thing is missing: you have to make sure she eats plenty of good food. See that she eats plenty of eggs and milk, vegetables and fruit, lentils and meat whenever you can afford it. That way she will gather strength."

Wilma's family took the doctor's advice. They all agreed together that even if it cost a little more it would be worthwhile to get plenty of good nutritious food for Wilma. "We should have thought of this from the start,"

said Wilma's mother. Wilma's father said "I can work some extra hours and earn enough to buy good food for Wilma. It will be worth it, to see my daughter walking tall and proud."

There is not enough time to tell all the stages of Wilma's recovery. It was a long time before she could run, but when she reached that point she was hardly still for a moment. "I've lost years of running," she said, "I have to make up for lost time." When Wilma went to school she soon was selected for the school sports team. The physical education instructor gave her the name "Mosquito" because Wilma was always buzzing around, never still.

Wilma had to pay off a debt to her family, and the way she chose to do it was by running. "All my family, mother and father, brothers and sisters, uncles and aunts, gave me their time and caring to massage my leg and to help me when I could not even walk. Now I'm going to show them that their effort was worth it. They'll be proud of me." Wilma trained as an athlete, running in all her spare time.

Wilma became school champion at sprinting. Then area champion, state champion, and finally she was selected to represent her country at the Olympic Games. There she broke records by winning four gold medals. Wilma never forgot that it was all thanks to the efforts of her family, poor people who could give no special treatment to her but who did what they could willingly and lovingly.

(Second voice):
Wilma Rudolph won her gold medals for two sprints, relay and long jump at the Olympic Games at Rome in 1960. There may never again be a world champion who started off with a paralysed leg, but the fact is still true that children who have been paralysed after poliomyelitis can be helped back to mobility if their family is willing to make the same efforts that Wilma's family made.

BROADCAST NUMBER 5 : THE BLIND CHILD

Interviewer: Today we are going to hear the story of a young man who was born blind and who grew up in a village. Abdul Ghani, tell us your story.

A.G.: I am Abdul Ghani son of Abdul Mohammed. I have been blind from birth, and I am now 28 years old. I am working as a bicycle repair mechanic in this town. I grew up in a village where there was no knowledge about teaching blind children. By the mercy of God my family decided that I should be given the chance to learn a trade. I remember when I was a child I overheard my grandmother say to my mother that I should be a beggar when I grew up. I did not know what a beggar was, because I had never seen one. That evening when the family were all present I asked "What is a beggar?". I could tell from the silence that I had asked an awkward question. If you are blind, you listen closely to sounds. I knew that everyone in the house had stopped whatever they were doing. My father said, "Abdul Ghani, why do you ask what a beggar is?" I told him, "Somebody said that I should be a beggar when I grew up". Then my father was angry. I have never seen a man's face when he is angry, but from the sound of the voice I guess that his face must be twisted and his muscles tense. My father said, "No son of Abdul Mohammed will be a beggar. If God has sent you into the world without eyes, then God will give you more skill in your hands and your ears. We will find a trade which you can practise and earn your bread. Never again say the word beggar in this house."

Three days later my father and my uncles left the village and travelled to the city, one day's walk over the hills to the main road, then half a day's travel by bus to the city. My mother told me this later on, when I was older. In the city my father visited several doctors and teachers, making enquiries about any trade or skill that a blind boy could learn. For several days he went here and there talking to people without finding what he wanted. Finally he met an old doctor who told my father that he too had been interested in the education of the blind when he was a young man. He had travelled abroad and had visited an institution where blind children were given their education and were trained to make baskets and to weave cloth and to repair cane chairs. My father questioned the old doctor closely about how the blind children were trained. When he came back to the village, my father addressed the whole family. He said "We have learnt that it is possible for a blind child to get training so that he has a trade. We did not find a teacher, but we understand the method which was described to us. We will all take part in teaching Abdul Ghani. He will get his training right here in this house and in this village." My uncles all agreed with this plan.

Int.: Abdul, how old were you at this time? And what had you done up to then?

A.G.: I was quite young, only 6 or 7 years old. Up to that time I had done nothing. I could feel my way around the house, but my family did not allow me to roam about, for fear that I might trip and hurt myself, or break something. I had learnt to express myself and say if I wanted food or toilet, but my family did not often talk to me. Many of the things they said were impossible for me to understand, because I could not see what they were talking about.

Int.: So how did you come to understand their words?

A.G.: My father told me this later on. When he came back from the city he said to the family, "It is now clear what we should have done right from the start, when Abdul Ghani was a baby. We have lost a few years, but now I know what to do and we will start today. We must all talk to Abdul Ghani, plainly and clearly, telling him what is happening around the place. He must feel with his hand or with his ears whatever we are talking about. He must walk in every part of the house and every part of the village, and we shall tell him what is there and he shall hear and touch and smell and taste.

For example, said my father, when mother is preparing bread, Abdul Ghani shall feel and taste the flour, the salt, the water and the name of each thing shall be told to him. He shall feel the dough and shall help to knead it. As his mother works, she shall say whatever she is doing. My father continued: Abdul Ghani will come with us when we work in the fields. His brother will take care that he does not bump into things or fall into the ditch while he is walking. Also we will get him a stick with which he can feel the walls and the path. Whatever his stick strikes against, we will tell him what it is and he can feel it with his hand. When the path turns to the left or to the right, we will tell him. Together with him we will count how many paces there are from the house to the corner, from the corner to the bridge, across the bridge and to the field, and so on. If a dog barks or a bird sings, we will tell him the name of the animal, and describe how it runs or flies.

In this family there are 11 persons, and 10 of us have eyes. Whatever we see with so many eyes, the same will be told to Abdul Ghani. When we speak to him, we will first say his name so that he knows we are speaking to him and not to another person. When we say the prayers, we will show him what movements and positions we adopt, and he will say prayers with us.

Int.: Abdul Ghani, how did this work out?

A.G.: I do not remember much about what happened to start with. It was like a torrent of words hitting me. I became confused with being told too many things from every direction. Several people would be speaking at once.

I was taken outside the house and there were many unfamiliar sounds and smells and voices. So I became afraid and would stand still with my hands over my ears and eyes, to protect myself. Then one of my uncles understood what the problem was and spoke to my father. He told him that my training should go step by step, and that they should not tell too many things at one time. One thing should be told until I understood it, then another thing could be told.

This same uncle is a very wise man. He wanted to understand how the world seemed to me, so he tied a bandage over his own eyes for one whole day, and moved about the house. Then he could understand more easily some of the problems I faced. It was he who found a long slender stick for me, which I can easily balance in my hand and which tells me where I am along the road.

Later on when I had become accustomed to moving about, I used to play a game with my brothers. In the evening when we were at home, we would pretend to be walking from the far end of the village, and we would count the number of steps and describe from memory every sight, sound and smell at each stage on the way home. When I had practised this game, I could remember things that they forgot, like the sound of hens clucking as we passed one old woman's house, the smell of spices at the grocer's shop, the feel of one loose plank as we walked over the bridge.

Int.: So you came to understand everything that your family spoke about?

A.G.: I did not understand everything. Remember, I cannot see. My little sister used to play tricks on me like this: she would give me a big orange and a small grapefruit, and ask me which was which. I could not tell by the size and feel of them, but my nose would tell me which was which. Then she asked, "Which one is yellow?" That I could not tell her, because I cannot tell what is the colour of anything. My uncle tried to explain colour like this: even if two people say exactly the same thing, their voices have a different sound. In the same way, two objects may be exactly the same, and feel exactly the same, but the eye can see some difference in that one of the objects is red and the other is black. But I have never seen this.

Int.: I would like to know more about how you developed your skills and what advice you would give to a family having a blind child. Will you return next week and tell us more?

A.G.: I shall be glad to do so.

BROADCAST NUMBER 6: BLIND YOUNG MAN

Last week we interviewed Abdul Ghani son of Abdul Mohammed, who has been blind from birth. He is now working as a bicycle mechanic. When he was younger, his family decided to help all together in his education and training. Whatever they saw and whatever they were doing, they used to explain it to Abdul Ghani. He would also feel everything with his hands. So he came to understand the world. Abdul Ghani is here again today. Abdul Ghani, how did you come to be a bicycle mechanic?

A.G.: I did not immediately become a bicycle mechanic. I used to help my brothers crop farming in the fields. My father marked out an area and placed rows of small stakes in the ground three metres apart. Pieces of string were tied between each stake. By using my stick, I learnt my way around this area. I knew where to make the ridges of earth for the crop, and I could feel with my stick if weeds were growing. I started with a very small plot of land, I ploughed and shaped the ridges and furrows and planted seeds. Then my father put stakes and cords over a larger area. To tell the direction from where I stood, I asked for the cords to be tied at different levels on the stakes, some higher some lower and some running diagonally. By tapping the cords with my stick I could understand where I was and I knew what work to do in each place.

Interviewer: Did you meet with any problems?

A.G.: Of course, I did not learn all this in one day. It took a lot of practice. Often I stumbled and fell down. Once I broke my wrist in falling. Then my grandmother said to the family "Why are you forcing the boy to work in the fields? Now he has injured himself. If it was the will of God for Abdul Ghani to be a farmer, he would have been born with eyes in his head." This caused a great argument in the family. Finally my uncle said "Nobody is forcing the boy to work. Neither does religion say that the blind person must not work. It is a matter of choice. What does the boy himself say?" I said that I wished to work, and that nobody in the world would stop me from working.

Interviewer: What did the other people in your village think?

A.G.: In the early days I heard several different views. Sometimes people give their views when I am present, as if I were not there or as if I were a child. Then they are surprised when I speak up for myself. Some people used to laugh when they saw me tapping the cords to find my way around my piece of land. They did not think I could grow anything. I enquired the names of those people. My brothers told me the names, and they wanted to go and pick a quarrel with those people. But I said "No, leave it to me". Later on after I had learnt to farm my land, when harvest came, I sent a gift of my crops to every person who had not believed that I could grow anything.

Interviewer: (laughing) How did they respond?

A.G.: They gave a feast in my honour. They announced to the elders of the village that Abdul Ghani son of Abdul Mohammed has become a big man, a farmer who produces crops and gives out gifts. But I said to them "Let us give praise only to God. By the will of God I was born without eyes. My father and mother and brothers have all helped, and by the mercy of God I am now able to work."

On another occasion some boys altered the cords on the stakes, to confuse me. If you are blind, you learn to tell your direction and whereabouts by other means. I feel the sun on my face, I hear the crows cawing in a clump of trees, I feel the direction of the wind. Thus I knew that somebody had altered the cords. My brothers caught those boys and wished to thrash them. But I said "What benefit to me, if they are beaten? Have they been to school? Can they read?" Two of them could read. "Very well," I said, "you will come every day in the evening and read to me from your schoolbooks. I will learn more about the world, about my country and my people." So I had no more trouble from the boys, because I saved them from a beating. And they read to me everything that was in their books.

Interviewer: Is this how you now come to be working here in the town?

A.G.: My uncle saw that I wished to learn more, so again the family had a long debate about what I should do. My father and my uncles again made a journey to the town and I accompanied them, to enquire about occupations for blind persons.

Interviewer: What was wrong with farming? You had learnt to do that work very well and to grow crops.

A.G.: Still to this day I have a small garden in my uncle's house in this town, in which I grow vegetables. But my father said, "The world is changing. Up to now we have lived as our grandfathers and great-grandfathers. But for our grandsons, life will be different. Many will go to the towns and cities. They will see and do things which were never before done. Therefore it is right for Abdul Ghani to learn a modern trade. After twenty years have passed, all our neighbours will be ploughing with tractors, but it will be hard for a blind man to manage a tractor. Let us find a modern trade, so that he will become independent throughout his life."

Many things were suggested. I believe now that I could have learnt any of those things. In the Western countries, blind people operate computers and the most advanced type of equipment. But I am a humble person and I have no such ambition. In one of the books read to me by the schoolboys there was a chapter about

bicycles. The bicycle is the transport of the ordinary man. So I said to my family "Let me learn to be a bicycle mechanic. This work can be done sitting in one place. The tools are not expensive. I will learn the shape of every part, and how each part is fixed."

So I sat together with my uncle, taking an old bicycle to pieces and assembling it again. It was more difficult than I expected. I had felt bicycles with my hands, but I did not know that there were pieces hidden inside. There are ball bearings inside the moving parts. There are tubes inside the tyres. It took me several months to learn how to do this work. For example, when the pedal of a bicycle is jammed and will not turn, I unscrew the pedal. I have many small wooden trays arranged on the floor by my side. In one of them I have pliers. In another box I have spanners. In another I have screwdrivers. When I take the pedal to pieces, I lay out the pieces in order, counting them as I do so. By this means, when I have cleaned and adjusted and oiled the pedal, I put it together again, counting every piece so that I do not miss out any ball bearings, nuts or washers.

People who have brought their bicycle to me for repair have found that my work is good. They have told their families. By this means I have become well-known in this town, and I have gone into partnership with another young man. His legs are paralysed, but he sits on a trolley and works with his hands. We have plenty of repair work to do.

Interviewer: Abdul Ghani whenever my bicycle needs repair, I will certainly bring it to you!

BROADCAST NUMBER 7: THE DEAF CHILD: DIAGNOSIS AND GENERAL

In the past few weeks we have talked about children and young people with different disabilities. First of all we looked at the fingers on our hand, and saw that one of them is smaller and weaker than all the others, but we do not disregard it simply because it is small and weak. In the same way one child out of every ten on average has some disability, and needs extra care and help from its family and the local community. We heard from the parents of one such child who is mentally retarded. They were given advice on how to help their child at home. Those parents will be coming back in a week or two, to report on how they have got along with the suggested training of their child.

We heard from a village malik about the problem of fits in his village, and what was done about it. The week after that the story was told of a remarkable little girl who was paralysed as a result of polio. Her family engaged together in a programme of home rehabilitation, and that little girl overcame her disability to become a champion athlete. For the past two weeks we have been hearing about blind children and how to help them overcome their disabilities.

This week we look at ways of helping the child who cannot hear properly. Most of the advice given concerning all the other disabilities applies to the problem of deafness as well. Whatever the disability, the child needs a lot of love and encouragement in order not to feel depressed and isolated. The child needs to join in normal, everyday activities as far as possible, and to be treated as normally as possible. This is certainly true of the deaf child. The deaf child gets information principally through seeing, since the ears are not functioning properly. The more the deaf child sees of normal, everyday behaviour, the more he or she will understand and copy. Therefore it is essential that such children be involved fully in every part of ordinary life.

Let us talk with the family of one deaf child. Jehanzeb Khan, when did you discover that your daughter had difficulty with her hearing?

J.K.: Bilkees was quite small, about four years old, when we took her to the doctor. My mother had thought for several months before that there was something wrong, but my wife did not find any problem. Bilkees was our first child, and we did not have much experience to compare her with. When she was a baby she made the sort of squeals and babbling noise that babies usually make, so we did not imagine anything was wrong. Later on she became very quiet, and did not start to talk at the time you would expect. My wife began then to wonder if Bilkees was mentally weak. But she always looked very alert. From very early on Bilkees would follow with her eyes whatever was happening, so I did not think that she could be mentally weak.

My wife said "When Bilkees is ready to talk, she will talk." But my mother got worried and nagged at us to see the doctor. Finally, Bilkees got a very bad cold which never seemed to clear up. There was a little pus coming from one ear, and Bilkees kept rubbing it. So we went to the doctor and explained the problem. He did a few tests. The tests were so simple, we could have done them ourselves if we had thought of it. The doctor told us what to do. Bilkees sat on my wife's lap, while I stood in front of her holding a toy. I was closely watching her eyes while she looked at the toy. The doctor stood to one side behind Bilkees and her mother, and rang a little bell. I was watching Bilkees and her eyes did not move from the toy even though the bell sounded behind her. It was as simple as that. From that moment I knew she was deaf.

The doctor tried a few other sounds, like rattling small stones in a plastic cup, and crushing up a newspaper, behind Bilkees' right ear and then her left ear. One time Bilkees did look round, but that was my fault. I looked away from her to where the doctor was standing. That gave Bilkees the clue that something was happening behind her, so she looked round. But she had heard nothing.

Doctor: You have given a very clear description. I must congratulate you on making such close observation of your daughter. In fact, that is one of the most important activities that all families with a handicapped child should do: to observe closely what their handicapped child actually does or does not do. What was the next step you took?

J.K.: The doctor said that there were several things that might be wrong, and we should treat them one by one. First he gave some medicine for Bilkees to clear up her cold and the pus in her ear. This medicine was effective after a few days. The doctor told us to come back when the cold had gone. When we saw him again, he cleaned out both the child's ears using warm water in a little pump. Then he went through the same hearing tests again. Bilkees sat on her mother's lap while I stood in front keeping her attention with a toy and watching her eyes. This time there was a different reaction from Bilkees. She could hear some of the sounds at one ear, but nothing with the other ear. So we asked the doctor what did all of this mean.

He told us that there are two different sorts of deafness, and he explained it in a very complicated way and we could not understand a word of it. I asked him straight out: Is she deaf, or is she not deaf? He said that one ear is completely deaf, and always has been deaf. The other ear is partly working, but it had stopped working due to the cold and infection and blockage with wax. Once he had cleared up the infection with medicine and had removed the wax with warm water, that ear had begun working again, but only partly working.

Doctor: This is true of most deaf children. Even if much of their hearing ability is lost, usually some part remains. Even that part can be temporarily lost due to an infection or dirt in the ear. Whatever hearing remains, it is important to use it as far as possible. If one ear is working, make sure you talk into that ear. Make sure that the ears are clean and that any colds or infections are treated quickly.

It was fortunate that Bilkees' mother and grandmother did take action and see the doctor when they suspected that the child had some problem. The sooner it is detected, the better. All parents ought to check their children's hearing if they have the smallest suspicion that there is any problem. Families often think that a child's hearing is okay simply because the child reacts to a loud noise. But the child may be unable to hear quiet sounds or high pitched sounds, with the result that he or she misses a great deal of what is said, whether at home or at school.

Mr. Jehanzeb, you were very observant when the doctor was testing Bilkees' hearing. You noticed something which often gives false reassurance to families. It looked as though Bilkees had heard the sound made by the doctor behind her back, but actually you realised that she looked round only because she had seen you looking at the doctor. Deaf children are often very sharp-eyed, since they have to rely on their eyes to tell them what is going on.

J.K.: Yes, we have noticed that, since Bilkees was a baby. The other thing the doctor advised us was to talk a great deal to Bilkees, and to use signs with our hands at the same time.

Doctor: Yes, that is important. We now know that deaf or partly hearing children need to learn to communicate in every way possible. This is a big subject, which needs plenty of time for discussion. Let's cover it more fully in next week's talk.